Children and Family Series

Count Us In:

A Demographic Overview of Childhood and Disability in Canada

L'Institut Rocher Institute

COUNT US IN!

A DEMOGRAPHIC OVERVIEW OF CHILDHOOD AND DISABILITY

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About

L'Institut ROEHER *Institute*

Canada's National Institute for the
Study of Public Policy Affecting
Persons with Intellectual
and Other Disabilities

L'INSTITUT ROEHER INSTITUTE IS CANADA'S POLICY RESEARCH ORGANIZATION promoting the equality, participation and self-determination of people with intellectual and other disabilities, by examining the causes of marginalization and by providing research, information and social development opportunities.

To fulfill this mandate, The Institute is engaged in many activities: research and public policy analysis; publishing; information gathering and dissemination; and training, education and leadership development.

The Institute acts as a centre for the development and exchange of ideas, all of which are founded on a new way of looking at disability in the context of a strong civil society. It critically examines issues related to the well-being and human rights of persons with disabilities. Based on its examination of these issues, The Institute raises awareness about the barriers that affect people's full participation in society and that prevent them from exercising their rights. The Institute also presents policy and program alternatives.

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FOREWORD

The Roeher Institute's "Children and Families Series" lays out a wide range of issues facing Canadian children and youth with disabilities and their families. And the series proposes concrete solutions to address these issues. ***Count Us In*** provides important baseline demographic information and a quick overview of key issues.

The report shows that families with children with disabilities continue to face struggles beyond those which most Canadian families face. It provides insight into issues of family stress and breakdown, poverty and reliance on public income support, although these are not universal features of families with children with disabilities. The report summarizes some of the difficulties parents face in their efforts to secure or hold onto paid employment while fulfilling their responsibilities as parents. It shows how some "equalizers" such as health care and education sometimes fail to reach the goal of ensuring equality of citizenship, benefit and participation where disability is at issue. And it summarizes how children and youth with disabilities are particularly vulnerable to various harms. Yet the voices of parents which echo throughout the report also give testimony to their love and commitment to their children who happen to have disabilities, and to the enrichment that these children bring into their families. Arguably, those voices and experiences need to be better profiled, listened to and heard.

Other publications in this series lay out specific, practical and what we believe to be quite achievable measures to improve the situation of children with disabilities and their families. The present report concludes with a more general call to action. After all, disability can happen to any child and family – whether through illnesses or disease such as childhood cancer or diabetes, an auto accident, a child's fall from a piece of playground equipment, an unexpected technical crisis during birthing or surgery, a pill taken whose effect could not be foreseen by parents or physicians trying to stem a flu or other health problem, genetic factors, risks sometimes taken by children against their parents' wishes and counsel, household or broader environmental toxins, AIDS, the mother's poor general health during pregnancy, seriously deficient developmental opportunities in the family or community, or factors which in too many cases have not been identified or understood as yet.

The report recognizes that Canada has made significant progress in recent decades towards including and providing support to children with disabilities and their families. This progress is rightfully acknowledged internationally. However, more thoughtfulness and effort are needed. Too many Canadian children and families face inordinate difficulties because they live with the stresses, the acquired poverty, the health issues, the exclusion and the other markers of disability, even though these issues are becoming more widely recognized in Canada.

I would like to thank Mary Bunch, who co-authored this report, and Michael Bach who provided very helpful guidance and input throughout the course of the research. Perhaps above all thanks are due to the families we have consulted, the members of the research community who share common interests, the health care and other professionals, and the policy makers and

public officials we have had the good fortune to meet along the way who are committed to ensuring that all Canadians — irrespective of age or society's perception of ability — are fully included as equals in society.

During this time of shifting priorities, it is vitally important that we do not miss the opportunity to ensure that *all* children and families reap the benefit of the signs of renewed fiscal commitment at all levels of government to the healthy development of children. Common sense dictates that it's in everyone's interest. If we have come this far, together our compassion, vision, audacity and resolve can take us a bold step forward to ensure that *all* children and families are counted in.

Cameron Crawford
President

104-06054/

I.
INTRODUCTION

"Get to know him...he is a member of the community...he needs supports to utilize his talents to be a contributing member of the community. Any moneys spent on him are an investment in the community."

Parent interviewed for
Beyond the Limits

Canada has a large and growing population of children with disabilities, and families of such children. Like other children and families, they are diverse in many ways. Yet as a group they share many things related to living with a disability. Perhaps even more importantly, the opportunities and participation of children in their community, in school, and even in their own families varies according to the kinds of supports available to them, regardless of the type or severity of the impairment they have.

Through the last few decades, and now into the millennium, disability has been recognized as resulting from barriers to full inclusion in society. This report looks at how Canada is doing in including children with disabilities and their families in various aspect of community life.

The publication draws on a number of key sources from the literature and statistical analysis. Much of the non-statistical discussion was taken from two recent publications by the Roeher Institute that examined issues faced by children with disabilities and their families: *Beyond the limits: Parents caring for children with disabilities* and *Finding a way in: Parents on social assistance caring for children with disabilities*. Another important source was a study by Sharon Hope Irwin and Donna Lero entitled *In Our Way: Child Care Barriers to Full Workforce Participation Experienced by Parents of Children with Special Needs and Potential Remedies*.

Statistical data were drawn from a number of sources. Some data came from the Roeher Institute using unpublished data from Statistics Canada's 1996 National Population Health Survey (NPHS). Another importance source of statistics was the Canadian Institute of Child Health

1994 publication *The Health of Canada's Children, a CICH Profile*. The CICH used unpublished Health and Activity Limitation survey data (HALS). Other important sources included a publication by the Canadian Coalition for the Rights of Children (1999), entitled *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

We have come a long way in including children in the last few decades. It was not so long ago that most people with disabilities were segregated in institutions, "special" schools and sheltered workshops. While those days are not completely gone, parents and children now have many more options available to them. Many children with disabilities live at home with their families and attend a school or childcare centre in their own neighbourhoods. They grow up with friends in their neighbourhood, dreaming of their future education, jobs and relationships.

However, this book also shows that we have a way to go before all children are "counted in". Many children (and adults) with disabilities remain excluded from society. Even for those who live at home, the fight for equality and full inclusion continues. Many families of children with disabilities face

struggles well beyond what other families face, juggling multiple roles, providing ongoing support to their child, and battling system after system to gain, or retain, their child's inclusion and the services they need.

Having come this far, it seems we are now poised on the brink of further enhancing the rights and inclusion of children with disabilities and their families, or reverting back to the old ways of institutionalized care. Indeed, in a number of provinces and territories new institutions are being built. Furthermore, budget cuts to services like education, health care and social supports threaten to turn back the clock and reverse the trend toward inclusion.

> *"I want them to have a life. They need opportunities to develop. This is not possible for me to do without needed supports and services."*
>
> Parent interviewed for
> **Beyond the Limits**

Like other parents, parents of children with disabilities want their children to have basic rights of citizenship. They want their children to live with dignity, security and freedom in a democratic country. Parents do not want to be poor but instead want adequate incomes for their families. Most parents would like to have access to the social supports that they and their children need for their families to flourish, whether these supports are health care services, social services or the informal support of family and friends. Most parents want a decent education for their children. And most want their children to be free from abuse, threats and violence. These are the same things needed by children with disabilities, and their families, to live inclusive lives with full citizenship.

II.
WHO ARE THEY?

TABLE 1.

Rates of Reported Long-Term Health Conditions within the Total Population 0-14 years, Canada, 1991

	Rate/1000 population
Total with Disabilities	69.8
Learning	17.3
Behavioural/emotional	8.4
Mental handicap	6.9
Heart Disease	5.3
Epilepsy	2.4
Cerebral Palsy	2.3
Kidney Disease	2.2
Other lung disease/condition	1.7
Missing limbs	1.5
Diabetes	1.1
Arthritis/rheumatism	1.1
Paralysis	1.1
Spinal bifida	0.8
All other	8.3

N=5,579,895

From 1991 HALS Children Survey (CICH 1994).

In the mid 1990s, estimates suggested that there were about 560,000 children and youth (up to the age of 19 years) with disabilities in Canada.** [1] There are differing views about how many families have children with disabilities, but it is likely that the figure falls somewhere between 5 and 20%[2].

Children with disabilities and their families are as diverse as any in the spectrum of Canadian families, and each child with a disability is unique. Children differ by gender, ethnicity and culture, personality and interest. They are members of different types of families in various socio-economic and geographic and community contexts.

Though statistics on disability and race or cultural background were not readily available, like all other children, those with disabilities are racially and culturally diverse. In Canada, 5% of all children are First Nations or Metis, 5% were born in another country, and 7.5% speak neither French or English as a first language.[3]

The main experience that they share is that of living with a disability. That is not to say that disability is experienced in the same way by every child and family. There are many different types of disability, with different levels of severity. Disability may involve a child's vision or hearing, their mobility, their development, their learning and so on. The most common type of long-term condition[4] among young Canadian children (0 to 14 yrs) reported in HALS 1991 is a learning disability, especially among boys, with just over 17 of every 1,000 children reporting this type of impairment. Over 8 children per thousand have a behavioural or emotional condition, and nearly 7 per thousand have an intellectual disability or "mental handicap".[5]

Overall, 4% of youth (15 to 19 years) had some form of learning disability, mental, emotional, psychiatric disability or developmental disability in 1991. Just over 2% had a mobility disability, another 2% had a

Table 2.

Disability Rates of Youth within the Total Population 15-19 years, Canada, 1991

Nature of disability	Percent
Learning, mental, emotional, psychiatric or developmental	4
Mobility	2
Agility	2
Speaking, hearing or vision	3

From 1991 unpublished HALS Statistical data (CICH 1994).

disability affecting their agility and nearly 3% had a disability which affected their speaking, hearing or vision.[6]

In terms of severity of disability, of the 7.2% of Canadian children (under the age of 19) who were disabled in 1991, 85% had mild, 11% had moderate and 4% had severe levels of disability.[7]

Endnotes

[1] In 1996, there were an estimated 560,000 children and youth **aged** 0-19 living in Canada who were disabled in some way. This figure is based on respondents who have been flagged as having "activity restrictions" in Statistics Canada's 1996 National Population Health Survey. This definition does not coincide exactly with the definition used in the Health and Activity Limitation Survey and probably **underestimates** the prevalence of childhood disability.

[2] Irwin, Hope Sharon and Donna S. Lero. (1997). *In Our Way: Child Care Barriers to Full Workforce Participation Experienced by Parents of Children with Special Needs and Potential Remedies.* Wreck Cove, Nova Scotia: Breton Books.

[3] Canadian Council on Social Development. (1999). *The Progress of Canada's children into the Millennium: 1999-2000.*

[4] ***One person may report more than one condition.

[5] Drawn from the HALS 1991 Children's Survey, by the Canadian Institute of Child Health. (1994). *The Health of Canada's Children, a CICH Profile.* Second Edition. Ottawa: Canadian Institute of Child Health.

[6] Drawn from the HALS 1991 Adult's Survey, by the Canadian Institute of Child Health (1994). *The Health of Canada's Children, a CICH Profile.* Second Edition. Ottawa: Canadian Institute of Child Health.

[7] Canadian Coalition for the Rights of Children (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

III. FAMILY INCOME

Poverty

While children with disabilities may live in families in various economic circumstances, children with disabilities are more likely to be poor than other children. The following figures, most of which are drawn from the National Population Health Survey, point to some alarming realities for many families of children with disabilities.

For one, children with disabilities are more likely than other young people to be in families at the lower end of the income scale (28.8% compared with 17% who live in households where the total income is in the lower-middle and lowest income quintiles).[8] To look at this another way, poor children are over 2.5 times more likely than children in high-income families to have a problem with vision, hearing, speech or mobility.[9]

Poverty may be a particular issue for families headed by parents who face restricted opportunities because of their gender, race or ethnicity, sexual orientation, family status or other factors linked to historic disadvantage. Families headed by single parents (especially mothers), for example, are at greater risk of poverty than two-parent families. Just over 70% of children from lone-mother families lived at or below the official Low-Income Cut-off (LICO) in 1994; in contrast, only 16% of children with two parents lived in low-income families (National Longitudinal Survey of Children and Youth). They are also more likely to depend on government income support than two-parent families (Statistics Canada 2000). In the 1996 Census, almost all lone-parent families (97.5%) reported income from government transfers, 39% of which was social assistance. Overall, 26% of lone-parent family income came from transfers compared to only 10% of income to husband-wife families (Statistics Canada, 1999).

The way poverty affects families may also differ depending on where they live, and what access they have to family and community support, and alternative economies (i.e. hunting, gardening, bartering). These circumstances are difficult to measure however, and data related to disability and race, or disability and alternative economics, for example, are not readily available in Canada.

> *"Being on assistance means not being able to feed or clothe my child properly. It means not being able to afford a movie. No toys, no books. Living so far below the poverty level it stinks."*
>
> Parent interviewed for
> **Finding a Way In**

One consequence of poverty is that families with low incomes may sometimes go hungry. Families with children who have disabilities are more at risk of this than other families. They are more likely than other families to have run out of money needed to buy food (15.8% compared with 8.2%) (1996 NPHS). Like other cash-strapped families in this situation, they may have to receive food from a charity such as a food bank or soup kitchen, and may be in situations where there is not enough food to eat on a regular basis.

TABLE 3.

Comparisons of families of children with disabilities and other families (NPHS, 1996)

Family characteristics	Children with disabilities	Non-disabled children
Dependent on government income support	16.9%	8.1%
Household income is in the lower-middle or lowest income quintile	28.8%	17.0%
Ran out of food money in preceding 12 months	14.4%	8.1%

Why are children with disabilities more likely to be poor than other children? Does poverty lead to disability, or does disability lead to poverty? It seems that both are true. Poverty leads to disability in a number of ways. People living in poverty have less access to enough nutritious food, both during pregnancy and as children grow up. They tend to live in areas or circumstances that may increase the risk of injury. They may have less access to health services, and lower literacy levels. All these things have been linked to increased rates of disability and ill health. Poor children, like children who are from visible minorities, are also more likely to be labelled as having a disability than children from more privileged families.[10]

Research also clearly indicates that disability leads to poverty. For instance, families with children with disabilities are more likely than other families to experience family breakdown, which is clearly linked to reduced income, as the next section of this report makes clear. Parents of children with disabilities also face barriers to participation in the paid labour force, or to advancing their careers that are not faced by other parents. This too shall be reviewed in more detail later in this book. Such families also must contend with costs that most other families do not face, such as those related to tutors, special diet, special clothing, transportation, babysitting, medications, supplies and equipment, and home adaptations.

Labour force issues

"We're not welfare bums,...we're caregivers providing a necessary service. Why can't we be recognized as such?"

Parent interviewed for
Finding A Way In

Some parents prefer— or simply have no other option — but to put their energies into caring for their children rather than into paid employment. Parents, especially single parents, often need to rely on government support to do so. Young people with disabilities are nearly twice as likely than other young people to live in families that depend on government, not employment, for their main source of income (16.9% compared with 8.1%) (1996 NPHS). This includes, for example, social assistance, workers' compensation and employment insurance. For many families of children with disabilities it makes more sense to use social assistance than to take a job with low wages, since they are entitled to receive more disability-related supports when on welfare. Thus, many parents simply cannot afford to work.

First Nations families of children with disabilities living on reserves experience some unique concerns related to social assistance. Social assistance on reserves tends to be lower than elsewhere, because federal guidelines recommend lower levels of support. Bands receive funding from the federal government for social assistance, but

not for any disability supplements. As a result, parents either move off the reserve to access supports, go without, or pay for it themselves.[11]

Throughout Canada, families relying primarily on government income assistance have a hard time making ends meet. Families who forego employment to provide care to their children, or who simply cannot find adequate employment, need to be supported financially so they can do so without living in poverty. Only Quebec, PEI and Newfoundland have income support provisions for parents who care for their children with disabilities.[12]

> *"I took time off without pay. I was told to make a choice between my family and my job. I have gone to half-time in my job, and took a years leave of absence."*
>
> Parent interviewed for
> **Beyond the Limits**

Many parents, however, want to participate in the paid labour force, and still be able to carry out their parental responsibilities at home. Yet they face particular barriers to equitable workplace participation. Many simply cannot juggle caregiving with their workplace responsibilities. In one study, the parents surveyed spent between 50 and 60 hours a week providing disability-related support to their child.[13] Employers are not required to accommodate parents who need to leave work from time to time to attend to the health and other needs of their children with disabilities. So in many cases, parents must alter their own commitments to their jobs, or leave employment completely. In a Canadian study,[14] 39% of parents whose children were disabled worked reduced work hours; 46% worked altered schedules; 68% turned down overtime and 72% passed up promotions because of their caregiving responsibilities. As a result such parents become disadvantaged in terms of pay, pension contributions, sick leave and vacation pay.

In many families, it becomes necessary for one spouse to leave the paid workforce and stay home to care for their child full time. In the above study, 64% of two-parent families that included a child with a disability reported one parent (frequently the mother) losing or giving up their job to provide supports to their child. This parent then experiences reduced income, loss of pensionable earnings, stress and isolation from staying at home, loss of career opportunities, and challenges upon re-entering the workforce at a later date.[15] The career mobility of parents who remain in the workforce is affected, but to a lesser degree. For example, they may decline overtime, extra responsibilities, or promotions that would require moving the family away from available supports and services.[16]

Parents describe a number of barriers to working — the main one being access to high quality, affordable and inclusive childcare. Respite care is another support that would aid working parents, as would access to other disability-related services that are comprehensive and flexible.[17] Qualities of the workplace also have an impact on parents' caregiving and job retention. Parents need measures such as control over hours of work; the flexibility to schedule meetings and appointments when convenient; access to benefit packages even if working reduced hours; provision to accumulate overtime to take time when needed; options for working from home and the assurance that, if necessary, they could go to their child immediately in order to balance their parenting and job responsibilities.[18]

Endnotes

[8] An income quintile represents the income range for one-fifth of all household incomes. If we take all households and rank their incomes from highest to lowest, then equally divide the number of households by five, family incomes fall into five broad groupings. Families who fall into the highest and lowest groupings represent the "highest" and "lowest"

family incomes on the five-point scale. Other families and their incomes fall into the lower-middle, middle and upper-middle groups.

[9] Ross, David P. and Paul Roberts. (1999). *Income and Child Well-being: A new perspective on the poverty debate*. Canadian Council on Social Development.

[10] For example, Smart and Well (1997), show that African American children are more likely to be labelled as having an intellectual disability than American children of European descent (26% compared to 11%).

[11] Canadian Coalition for the Rights of Children. (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

[12] Ibid

[13] Roeher Institute (2000). *Beyond the Limit: Parents Caring for Children with Disabilities*. Toronto: The Roeher Institute.

[14] Irwin, Hope Sharon and Donna S. Lero. (1997). *In Our Way: Child Care Barriers to Full Workforce Participation Experienced by Parents of Children with Special Needs and Potential Remedies*. Wreck Cove, Nova Scotia: Breton Books.

[15]

Ambert, Anne-Marie. (ed.). (1992). *The Effect of Children on Parents*. Binghampton, NY: Haworth Press; McKeever, Patricia, Jan Angus and Karen Spalding. (1998). *Raising Children who have Disabilities in Ontario: The Characteristics, Activities and Circumstances of Biological and Foster Mothers*. Unpublished Report.

[16] McKeever, Patricia T. (1981). "Fathering the Chronically Ill Child." *American Journal of Maternal Child Nursing*, March/April, pp. 124-128.

[17] Roeher Institute. (1999). *Labour Force Inclusion of parents caring for children with disabilities*. Toronto: The Roeher Institute.

[18] Ibid

IV. FAMILY LIFE

"I have gotten so much back we have to reconsider what we value. He is an inspiration ...I feel very blessed."

Parent interviewed for
Beyond the Limits

Children with disabilities are valued members of their families. While in the past many families were told their children should be institutionalized if they were disabled, today most children with disabilities live at home with their parents and brothers and sisters. While families with children with disabilities are like other families in many respects, with their own style, family dynamic, culture and preferences, there are certain experiences that families in this circumstance have in common.

Supports for families

Families of children with disabilities may be able to access special funding or tax credits and community-based services such as respite or home care to help them support and care for their children with disabilities at home. However these programs tend to have limited funding and provide access on a discretionary basis. Families do not have the clear entitlements to social services that they do for health care and education.[19]

A number of recent studies[20] show that families' access to disability-related supports is fraught with problems. Families say the means tests that determine eligibility are too rigid, and don't sufficiently consider individual family circumstances and disability-related costs. They also report that access to services varies between families and between regions, they are discouraged by long waiting lists, and that they often can't afford the costs of short-term relief care transportation and equipment costs.[21]

Access to home care, for example, varies across the country and even within provinces. Though the variability is difficult to measure due to a lack of reliable data, we do know that there is no consistent or coherent home care coverage, nor standards defining access to basic services.[22]

Where families live also affects their access to supports. Anecdotal evidence suggests that families of children with disabilities often need to move to urban areas to get support. In 1996 nearly 40% of children with disabilities under 12 years old lived in rural areas (compared to 32.2% of other children). After age 12, the share of all children with disabilities living in rural areas drops to 23.2%. For non-disabled young people in the same age group, 36.3% continue to live in rural areas.[23] This suggests that as children with disabilities get older, their families are more likely to move to larger towns and cities, perhaps to gain access to disability-related supports.

"The only time I have for myself is when she goes to sleep. It's a constant fight, except weekends when she's at respite. It's the only time I can relax."

Parent interviewed for
Finding a Way In

Families consistently report needing more respite care. Respite care involves services aimed at giving parents or guardians time off from caregiving. National statistics on access to respite care are not easily available,

but numerous smaller studies consistently indicate that the availability of respite services is inadequate. In one study of 50 families, 90% stated that respite care was one of the top things they need to support their children in the community, but the need is not being met.[24] Despite a large body of literature that shows the importance of respite in promoting well-being for families and community inclusion, issues related to respite care have changed little in the last few decades. Access is particularly difficult for families in rural areas and children who have particular support needs, for example due to complex health issues, or behavioural disabilities. Families with low incomes, and those who are from visible minorities also have less access to such services.[25]

Caregiving responsibilities

As a result of inadequate support services, families and other informal networks of supports are becoming more and more responsible for providing direct support to disabled family members. In Alberta, for instance[26], 40% of youth aged 12 to 19 reported that they had received care from family members or friends in the past 12 months because of a physical, emotional or mental health problem. Only 20.7% of young people without disabilities received such care. Among the young people with disabilities who received the care, most (61.2%) had received care from a relative or friend in the past month.

> *"I'm everything – I'm the playmate, storyteller, therapist, disciplinarian, advocate, cook, and parent."*
>
> Parent interviewed for
> **Finding a Way In**

Parents, and especially mothers, are responsible for much of the disability-related support. Many studies show the multiple responsibilities of parents as nurses, service coordinators, case managers, advocates, trainers and educators.[27] These roles require time and skill, and are often taxing on parents. In one study[28] parents of children with disabilities spent approximately 50 to 60 hours of their time per week on tasks related to disability[29], in addition to their other workforce or domestic responsibilities.

As in other Canadian families, the bulk of caregiving work in families with a child with a disability is still provided by women.[30] Mothers are up to ten times more likely than fathers to be defined as carers of their child with disabilities.[31] This means that previously waged work carried out in hospitals and institutions is now being carried out by mothers, for free. While some community based supports are available, families are expected to fill in the gaps in service that result from funding cuts and shifting models of care. So, while families are happy to have their children home, many parents, especially mothers, are stressed out and exhausted[32] by their many responsibilities. This affects the health and well-being of mothers and entire families.

> *"I should have had a nervous breakdown but I didn't have the time"*
>
> Parent interviewed for
> **Finding a Way In**

Impacts of disability on the family

> *"[Having a child with a disability] is the most wonderful thing that's ever happened to me. I found talents and strengths that I did not know I had. He makes people change ... life is a never-ending adventure."*
>
> Parent interviewed for
> **Beyond the Limits**

Parents love their children with disabilities and value them highly. They tend not to blame their stress and fatigue on their children, but rather on not having enough support.[33] Parents also point to many of the positive gains of caring for a child with a disability. They describe their experiences as deeply rewarding and satisfying, finding a

"new appreciation for life" through their relationships with their child, and becoming stronger and more resilient to life's difficulties.[34]

- In 1994 over 70% of children from lone-mother families lived in poverty, compared to 16% of children with two parents.
- Nearly 40% of lone-parent families were on social assistance in 1996.
- The vast majority of lone parent families are headed by women.
- **Single mothers are twice as likely to be poor than single fathers, and more than four times as likely to be poor than families with two parents.**

Yet the stresses of multiple responsibilities, lack of adequate support, and the juggling of multiple roles takes its toll on many families.

In some cases, insufficient support may lead to the placement of a child in a residential setting or in foster care. In one survey of 117 parents of children with disabilities conducted by the Canadian Association of Community Care, half the parents cited denial of respite and childcare services as reasons for out-of-home placement.[35] In another recent study of 100 children in care in Alberta, 57% of children in care in the study had accessed disability-related services in the past 12 months, and 65% were diagnosed as having at least one disability.[36] It is also worth noting that foster parents of children with disabilities typically receive better financial support from provincial authorities than natural families do.[37] In some communities the pressure to place children in care is even greater. First Nations families, for example, are frequently advised to place their children with disabilities in foster care in order for their children to gain access to needed supports.[38]

Another possible consequence of family stress due to insufficient support is family breakdown. Children with disabilities are over-represented in lone parent families (18.1% compared with 14.1%) (1996 NPHS). In this situation, families become even more vulnerable, as the risk of poverty is higher for lone parent families than for two-parent families. This is a particular concern for women, who head the vast majority of lone-parent families (Statistics Canada, 2000). In 1994, lone-parent families headed by women (56.8%) were nearly twice as likely to be poor than those headed by men (30.7%), and more than four times as likely to be poor than families with two parents (12.8%) (Canadian Council on Social Development, 1995).

Endnotes

[19] Unlike the previous version of the NPHS for 1994, the most recent cycle of the NPHS does not tell us about whether those in need of various "home care" supports such as help with bathing, housework, respite care or meal delivery, have needs that were not met in the past 12 months. So we are not in a position to clearly "size up" the magnitude of unmet needs for medical as compared with more general "health-related" supports for young people with and without disabilities.

[20] Canadian Coalition for the Rights of Children. (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?;* Roeher Institute. (2000). *Beyond the Limit: Parents Caring for Children with Disabilities.* Toronto: The Roeher Institute; Roeher Institute (2000) *Finding a Way In: Parents on Social Assistance Caring for Children with Disabilities.* Toronto: The Roeher Institute.

[21] Canadian Coalition for the Rights of Children. (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

[22] Ibid

[23] The Roeher Institute based on the National Population Health Survey of 1996-97.

[24] Roeher Institute. (2000). *Beyond the Limit: Parents Caring for Children with Disabilities.* Toronto: The Roeher Institute.

[25] Ibid

[26] The aim, here, is not to single out the situation in Alberta as being worse than elsewhere in Canada. Alberta was simply the only province that contributed additional funding to the NPHS for survey questions on informal supports provided by family and friends. The information was captured for Alberta only.

[27] Haverstock, Shannon Lee. (1992). *Learning to Care for Chronically-Ill, Technology- Dependent Children: Mothers' Experiences of Skill Acquisition*. Unpublished master's dissertation, University of Toronto; Roeher Institute. (2000). *Beyond the Limit: Parents Caring for Children with Disabilities*. Toronto: The Roeher Institute.

[28] In one recent study the Roeher Institute (2000) interviewed 50 parents of children with disabilities.

[29] Tasks included personal care, advocacy, coordinating care, and providing transportation regarding education, childcare, generic and specialized health services, therapies, recreation and leisure for their children.

[30] Indeed, the 1996 Census data shows that women tend to take on the bulk of unpaid work in communities, and much of this is in caregiving.

[31] Bowman, Dina and Melanie Virtue. (1993). *Public Policy Private Lives*. Canberra ACT: Australian Institute on Intellectual Disability.

[32] Mothers of children with disabilities are described as anxious, sad, burdened, exhausted, socially isolated, lonely and lacking self esteem (McKeever, Angus and Spalding, 1998). They report high physical and psychological stress, chronic fatigue, headaches, menstrual problems, digestive problems, depression, anxiety, interrupted sleep and irritability (Ambert, 1992; Guerriere and McKeever, 1997; McKeever, Angus and Spalding, 1998).

[33] McKeever, Patricia, Jan Angus and Karen Spalding. (1998). *Raising Children who have Disabilities in Ontario: The Characteristics, Activities and Circumstances of Biological and Foster Mothers*. Unpublished Report.

[34] McKeever, Patricia, Jan Angus and Karen Spalding. (1998). *Raising Children who have Disabilities in Ontario: The Characteristics, Activities and Circumstances of Biological and Foster Mothers*. Unpublished Report; Ambert, Anne-Marie. (ed.). (1992). *The Effect of Children on Parents*. Binghampton, NY: Haworth Press; Guerriere, Denise and Patricia McKeever. (1997). "Mothering Children who Survive Brain Injuries: Playing the Hand You're Dealt." *Journal of Social Psychology* 2(3), pp. 105-115; Krauss, Marty Wyngaarden and Marsha Mailick Seltzer. (1993). "Coping Strategies Among Older Mothers of Adults with Retardation: A Life-Span Developmental Perspective." In, *Cognitive Coping, Families, and Disability*. Ann P. Turnbull et al. (eds.). Baltimore: Paul H. Brookes.

[35] Canadian Coalition for the Rights of Children. (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

[36] Alberta Family and Social Services and the Alberta Association for Community Living (1997). *Children with Disabilities in Care: Summary Report*.

[37] Canadian Coalition for the Rights of Children. (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

[38] Ibid

V.
COMMUNITY LIFE

Children with disabilities and their families live in all sorts of communities around the country, and participate in community life to varying degrees. An important part of inclusion in communities for families and children with disabilities is the degree of access they have to the supports and services that are available to other Canadian children, such as childcare, education, health services and recreation.

Childcare

> *"There's no money for childcare. I couldn't get a paid job and get the childcare I need. It prevents me from going out and looking for any old job. I have to think of after school care, people to transport them to and from school. [And then the problem is] finding people skilled enough to take care of her, who will be able to keep her safe."*
>
> Parent interviewed for
> **Finding a Way In**

Families need childcare for many different reasons — so that parents can work, or rest, or 'get things done'. For children, childcare is a place to meet and develop relationships with other children, play, explore, and begin to prepare for entering the education system. However, Canada has no comprehensive system of childcare, despite rising numbers of women working outside the home, and a decline in extended family support as family and community patterns shift.

Many studies have pointed to the necessity of affordable childcare to enable parents to participate in the workplace. For example, one recent Ontario study found that good free childcare (and recreation programs) enabled single mothers to leave welfare at double the rate of the welfare population not receiving such assistance.[39] Yet there is a scarcity of affordable day care in this country, a situation which has gotten worse in many provinces in recent years.[40] In 1996, the number of licensed spaces in Canada accommodated only 18% of the number of children requiring childcare overall.[41] A 1998 report showed that regulated childcare provided for less than 8% of children under the age of 12 in Canada[42], though 65% of mothers who have children under six years of age are in the workforce.[43]

For parents of children with disabilities, accessing childcare can be even more challenging than for other parents. In one study on inclusive childcare, 73% of the parents reported difficulties finding appropriate care for their child. Seventy per cent had difficulty finding trained and committed caregivers, 68% have or had difficulty finding back-up care when an existing arrangement breaks down or a child or parent is ill.[44]

In 1991, about 35% of preschool aged children with disabilities were using childcare, and another 43% had childcare at some point. When in childcare, they were most likely to be in a licenced day care (16%). Otherwise, they tended to be cared for in their own home (10.4%) or a caregiver's home (9.9%).[45]

Childcare centres are not required to include children with disabilities, although some childcare centres are inclusive. Others may want to be, but deny certain children access because they simply do not have adequate facilities, staff ratios or trained staff to meet

the child's needs.[46]

One study found that most childcare centres supported some children with disabilities some of the time. However, they did so on a child-by-child basis, accepting some children with disabilities and excluding others.[47] In 1991, 12% of children 4 years of age and under who had disabilities and who needed childcare had been refused childcare service. Of these, two thirds were refused by a licenced daycare. The others were refused by caregivers in the child's home (38%) or the caregiver's home (27%).[48]

There is no clear policy for childcare in Canada, let alone inclusive childcare. In most provinces, childcare centres do not receive enough funding to provide inclusive accessible programs. Families face long waiting lists, refusals to admit their children, and fees that they cannot afford. Even when they have managed to secure childcare, they may encounter difficulties in getting their child to the centre and back home again, rigid hours of operation and inflexible curricula, and a lack of training among staff about disability.[49]

For many parents, especially if they have a child who is disabled, childcare outside of school hours is also an issue. It is difficult for many parents to work if they cannot find childcare after school, before school and in the evenings, particularly for parents who may work in shifts. A recent study which surveyed 50 families of children with disabilities found that only 12% of the parents reported having access to afterschool care.[50]

Health Care

The health care sector is one publicly funded service in Canada that is supposed to be universal and available equally to all. However, based on the 1996 NPHS, The Roeher Institute found that 12% of young people with disabilities aged 12 to 19 reportedly did not receive the health services they needed in 1996. Only 2% of non-disabled young people experienced similar lack of access to health services.

Other research conducted by The Roeher Institute has found that the health care system is not as well geared to the needs of young people with disabilities and their families as it is to others. There is a need to address discrepancies in health service availability, access and adequacy between people with and without disabilities. While doing so, care should be taken not to conflate disability and ill-health. To be certain, young people with disabilities tend to report more chronic health problems than other young people and tend to report that they are somewhat less well in terms of general health than other young people. This might be expected. Overall, however, the vast majority of young people with disabilities are reportedly in good, very good or excellent general health (88.3%). The general health of only 1.7% is reportedly "poor" (NPHS). There is some risk that disability will[51] continue to be pathologized and re-medicalized in view of the emerging trend across the country for departments of health to be given ever larger responsibilities not only for health but also for social services programs.

Education

All children in Canada have a right to attend school. In fact, school attendance is compulsory until the age of 16. Most children with disabilities who are legally required to attend school do so in some form. Children with disabilities who are too young for compulsory education may be less likely to access preschool (kindergarten) than older children, and their non-disabled peers. Local education authorities in all provinces are funded to provide one year of preschooling, but most provide little support for children with disabilities.

> *"She's now in a neighborhood school, same as her sister, in a class of 26 with an aide,*

and she does just wonderful. The principal is excellent.... It took blood and guts to get her in the school she's in now – a whole year of tears and fighting for the rights of my daughter."

Parent interviewed for
Finding a Way In

For older children, advances have been made in recent years to close the education gap between young people with and without disabilities. Among young people aged 12 to 19, the vast majority are at school, college or university (84.7% of young people with disabilities compared with 86.5% of their non-disabled counterparts). On balance, the education level of young people with disabilities is almost equal to other young people. About 20% of both groups have graduated from secondary school or have moved on to pursue post-secondary studies (1996 NPHS).

There is some way to go before the education gap is closed altogether, however. In 1991, disability interfered in some way with the education of 44% of children with disabilities between the ages of 5 and 14 years. For example, they began school later than other children (7%), their schooling was interrupted for long periods (8%), or it took them longer to achieve their present level of education (29%). There is still about a 2% gap between the overall participation of young people with and without disabilities in secondary and postsecondary education. The size of the gap no doubt increases in some measure depending on the nature of the student's disability and the supports available at the schools in their community.

The proportion of students with disabilities in full-time studies is lower than among other students (91.1% compared with 98.4% respectively). Some students may be opting to study part time because this is consistent with their issues of health, physical stamina, learning difficulties, and so on. But some may be in school on a part-time basis because inaccessible transportation makes it difficult to get to and from classes more regularly, or because they have difficulty securing adequate personal and technological supports for participation in educational programming, or because they simply have a more difficult time securing the needed financing for education where disability is an issue.

Where a child learns is another issue that impacts on development. Not all children are included in a regular classroom in their own neighbourhood. While there are provincial and territorial commitments to inclusive education, enforcement and assessment mechanisms need improvement. In most provinces and territories, inclusion in regular classes is determined on a case-by-case basis, and some children are more likely than others to be included. For instance children with physical disabilities are more likely to be successfully included than those with multiple, developmental or emotional disabilities. Other factors can play into these decisions as well, depending on the region and the individuals involved. For example, race, language, or family income could play a role in decisions to include a child in a school, since such decisions are usually made by individual administrators at the school or district level. Inclusion is not guaranteed, and even in provinces such as New Brunswick where inclusion is a legislated requirement, the extent and form of actual inclusion depends to a significant degree on school districts and individual schools rather than on provincial standards. In 1991, 5% of children with disabilities aged 5 to 14 attended segregated schools, and another 37% were in special classes at regular schools. Nearly 11% had to leave their home communities to go to school.[52]

TABLE 4.

Types of schools attended by children with disabilities 5-14 years in 1991.

Attended Regular school	58%
Attended a segregated school	5%
In special classes at regular schools	37%
School in a community not their own	11%

If young people with disabilities are to make a reasonably smooth transition from high school to postsecondary education and training, and ultimately into the labour force, intentional public policy and program measures will continue to be needed across several sectors to increase the chances of this happening. There is presently very little information available about whether these measures are in place, their adequacy and whom they target.

Recreation and leisure

An important part of belonging to a community is being able to take part in social and leisure activities with other community members. In part this simply involves being able to access community spaces, such as stores, shopping malls, parks, playgrounds and public sidewalks. Children and youth with disabilities may face barriers engaging in even these simple activities that many take for granted. In 1991, according to (HALS), 7% of children had difficulty taking short trips outside their home.[53] The accessibility of community/public spaces is inconsistent. Building and other accessibility standards and codes exist, and are applied to many new spaces as they are constructed. However, even when efforts have been made for accessibility, the codes were designed with adults, not children in mind. Statistics were not identified which suggest the percentage of urban or rural spaces that are barrier free, in general or specifically for children. Anecdotal evidence suggests that many barriers exist, but accessibility may be improving over time as the public becomes more aware of these issues. For example, the Canadian Standards Association is working to address lack of accessibility of children's play spaces,[54] the National Transportation Act ensures accessibility of airports, trains and inter-provincial buses, and the Building Code (s.3.8), adopted by some provinces, requires that new buildings be barrier free. Lack of compliance with such provisions, however, is an ongoing issue.

> *"She'll be starting Special Olympics. She can swim; she can go off the high diving board. We let her go off the high diving board, we let her put wood on the fire, we let her fish, and she's right down there in the white water. We tried to get her up water skiing. They said I was overprotective because I was upset by her bruises."*
>
> Parent interviewed for
> **Finding a Way In**

Recreation and leisure also involve participating in organized activities with other children. Some recreation opportunities exist which are designed specifically for children with disabilities. Organizations such as the Special Olympics and Easter Seals may run programs and camps that families can access. Inclusive generic programming is also becoming more available. For instance, child and youth organizations like the Scouts and Boys and Girls Clubs and the YMCA and YWCA have made efforts to be inclusive, as have municipal parks and recreation programs and various sporting organizations. Overall, however, progress towards inclusion has been inconsistent; though access to recreation programs seems to be gradually increasing, children continue to face barriers. Typically, barriers to recreational activities include lack of specialized equipment, a lack of accessibility standards for play spaces, and insufficient staff training and staff ratios. Even when a program is inclusive, children may have a difficult time getting there because of a lack of accessible

transportation. For those in small towns and rural areas opportunities for leisure activities are especially limited.[55]

Overall, 26.5% of children aged 0-4 years and 57.8% of children aged 5 to 14 years with disabilities participated in community physical recreation programs in 1991 (HALS).[56] Over 40% of youth with disabilities would like to participate in more leisure activities; and almost half want to be more physically active. Cost and lack of opportunity were major barriers. [57]

Endnotes

[39] Browne, G., C. Byrne, J. Roberts, A. Fagni, W. Watt, Y. Ashford, E. Jamieson and M. Wong. (1998). *Benefitting all the beneficiaries of social assistance is "within our reach": An RCT of the two-year effects and expense of subsidized versus non-subsidized quality child care/recreation for children on social assistance: Health and Social Service Utilization.* Ontario: McMaster University.

[40] Roeher Institute. (1999). *Labour Force Inclusion of parents caring for children with disabilities.* Toronto: The Roeher Institute.

[41] Duxbury, Linda. (1996). Presentation given at the Learning Partnership. Toronto, November.

[42] Childcare Resource and Research Unit. (1998). *Child Care in Canada: Provinces and Territories, 1995.* Ontario: University of Toronto.

[43] Roeher Institute. (1999). *Labour Force Inclusion of parents caring for children with disabilities.* Toronto: The Roeher Institute.

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[51] The Roeher Institute. (2000). *When Kids Belong: Supporting Children with Complex Medical Needs at Home and in the Community.* Toronto: The Roeher Institute.

[52] HALS data in Canadian Coalition for the Rights of Children. (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

[53] Canadian Coalition for the Rights of Children. (1999). *The UN Convention on the Rights of the Child: How Does Canada Measure Up?*

[54] Ibid

[55] Ibid

[56] Ibid

[57] Ibid

VI. SECURITY, VIOLENCE AND ABUSE

Issues of violence and abuse have garnered significant public policy and broad public attention in recent years. Violence against people with disabilities is becoming more widely recognized as a serious and pervasive social problem. A variety of violence prevention strategies have been developed to stem the problem, and police forces and community agencies are increasingly trying to adapt their services so they will become more responsive to these problems after the fact as they affect people with disabilities.

Abuse comes in many different forms, and happens in many different environments. Abuse may involve sexual, physical or emotional maltreatment. For children with disabilities, some forms of abuse may be subtle, and not as easily recognized by the law. For example, abuse may come in the form of restricted movement, invasive "therapy" or rough handling while receiving personal care (e.g., for washing, feeding, grooming, using the toilet). For any child, abuse could come at the hands of parents, teachers, health professionals and others.

Violence and abuse against children and youth with disabilities, however, has received very little attention, although they are more likely than other children to be physically or sexually abused.[58]

Among children with intellectual disabilities, for example, research has found that 39 to 68% of girls, and 16 to 30% of boys are subjected to sexual abuse before the age of 18. Rates of abuse are also high among children who are deaf, compared to other children. More than five times as many boys who are deaf are sexually abused than other boys (54% compared to 10%). Twice as many girls are abused when they are deaf (50% compared to 25% of girls who are hearing). Children with physical disabilities also may experience high rates of abuse. One study found that, of children with multiple disabilities who were in a psychiatric hospital, 39% had suffered maltreatment.[59]

While many children are at risk of abuse in their homes, children with disabilities may be at greater general risk because of the difficult circumstances common to their families. As a number of reports show,[60] many families of children with disabilities are isolated, burnt out and overwhelmed by strenuous caretaking demands and insufficient supports. Research shows that children with disabilities are more likely to be abused within their families when their families experience isolation (which may be increased by demands of caregiving), are overwhelmed by the demands of caregiving, lack opportunity to develop effective coping skills, or engage in difficult caring activities while lacking respite and other supports. Risk of abuse also rises when families face additional stresses (like unemployment), have a generational history of abuse, use corporal punishment or when substance substance abuse is involved. Abuse is also furthered by negative social attitudes toward disability.[61]

Population surveys tend to confirm that young people with disabilities are less likely on average to feel safe, and that they are less

likely than other children to be free from abuse, threats and attack.. For example, among youth aged 12 to 17 recently surveyed in Alberta (NPHS 1996-97), only 51% with disabilities say they "always" feel safe in the community, compared with 57% of other young people. Only 52.4% always feel safe at school compared with 60% of their non-disabled counterparts, and only 77.5% always feel safe at home while this is true for 85.9% of other young people this age. These findings need to be treated with caution owing to small sample sizes. As well, the findings should not be construed as casting a shadow over Alberta. Alberta was the only province to request that such questions be asked on the NPHS. Based on other research conducted by The Roeher Institute, the findings for Alberta probably reflect a much broader trend.

The following table shows the different patterns in perceived freedom from verbal abuse, threats and physical assault against young people with and without disabilities surveyed in Alberta in the NPHS.

TABLE 5.

Percent of youth, aged 12-17, with and without disabilities (in Alberta) who have *not* been verbally abused, verbally threatened or attacked in the past 12 months (NPHS 1996-97)

	with disability	without disability
Never verbally abused[62] at school/school bus	47.3%	61.0%
Never verbally abused outside of school	60.4%	73.0%
Never verbally threatened[63] at school/school bus	63.9%	74.9%
Never verbally threatened outside of school	78.1%	81.9%
Never physically attacked or assaulted at school/school bus	89.6%	91.7%
Never physically attacked or assaulted outside of school	84.5%	93.0%

Endnotes

[58] Ibid

[59] See Roeher Institute. (1995). *Harm's Way: The Many Faces of Violence and Abuse Against Persons with Disabilities.* Toronto: The Roeher Institute.

[60] Roeher Institute. (2000). *Beyond the Limit: Parents Caring for Children with Disabilities.* Toronto: The Roeher Institute; Roeher Institute. (2000). *Finding a Way In: Parents on Social Assistance Caring for Children with Disabilities.* Toronto: The Roeher Institute.

[61] Roeher Institute for the National Clearinghouse on Family Violence. (1994). *Violence and People with Disabilities: A Review of the Literature.* Family Violence Prevention Division, Health Canada.

[62] Responses defined as ones where "verbal abuse" occurred are ones where NPHS youth respondents reported that, at least once in the past year, someone said "something personal about you that made you feel extremely uncomfortable, not just friendly teasing?"

[63] Responses defined as ones where "verbal threats" occurred are ones where NPHS youth respondents reported that, at least once in the past year, "someone threaten[ed] to hurt you but not actually hurt you?"

VII.
CONCLUSION

Much has changed for children and youth with disabilities in recent decades. Today they are more likely to live at home with their families, attend their neighbourhood daycare or school, and spend time with their peers in their own communities than in previous years. There is much to be celebrated in how far our communities have come in their capacities to count children with disabilities in. Yet, there is considerable room for improvement in our efforts to support young people with disabilities and their families.

While there have been many advances in inclusion, families that have children with disabilities continue to face struggles beyond what most other Canadian families face. Young people with disabilities are more likely than other young people to be living in poverty, in families headed by a lone parent, and dependent on the income support system. Too many lack the money for basic necessities such as food, and may even have to depend on food banks and soup kitchens for daily essentials. Parents of children with disabilities are often not in a position to juggle responsibilities as caregivers and as participants in the paid labour force, yet the income support system does not account for their circumstances. Those with jobs, or who wish to be employed, have difficulty accessing the community supports which make it feasible to work for pay while fulfilling their responsibilities as parents. The rights of parents of children with disabilities to job accommodations and to protections against discrimination in the labour force are not recognized in anti-discrimination legislation. The sometimes limited availability and relative inadequacy of basic "equalizers" such as health care services can be more problematic for young people with disabilities and their families than for other children and families. Access to childcare remains tenuous for all children — especially for those with disabilities. An education gap, while narrowing, persists between young people with and without disabilities. And young people with disabilities are less likely than other children and youth to feel safe and to be free from abuse, threats and assaults.

In short, improvement has been achieved in recent decades to include and support young people with disabilities and their families. But much remains to be done.

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